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Reflections on an Impossible Profession: A First-Hand Account of the Development of Contemporary, Multi-Disciplinary Bioethics

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BOOK REVIEW:

IS THERE AN ETHICIST IN THE HOUSE? ON THE CUTTING EDGE OF BIOETHICS

Authored by: *Jonathan D. Moreno**

Is There an Ethicist in the House? explores a 25-year personal and professional journey through the field of bioethics just as it was getting off the ground. I was a young philosophy professor who found himself with a rare opportunity: to be part of a new field and help define its issues, as well as a new profession, helping to define its role. This work has taken me from the hospital bedside to congressional hearing rooms and presidential commissions. In these writings I reflect on my experience as clinical ethicist, medical philosopher, historian of medical ethics, and bioethics policy analyst.

REFLECTIONS ON AN IMPOSSIBLE PROFESSION: A FIRST- HAND ACCOUNT OF THE DEVELOPMENT OF CONTEMPORARY, MULTI-DISCIPLINARY BIOETHICS

Reviewed by: *Jennifer S. Bard***

Jonathan D. Moreno holds an honored place in American society as one of the most credible voices in the application of philosophical training to contemporary moral, ethical and legal problems in clinical medical care and human subject research.¹ This book relates his personal

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¹ He became a public figure following his appointment by President Clinton to the President's Advisory Committee on Human Radiation Experiments when he helped uncover a secret Government program of experiments conducted in the late 1940's through the 1960's on the effects of radiation on the human body. These experiments were conducted by the most prominent and respected medical researchers on un-

experiences making the transition from a philosopher to a bioethicist and reflects his views on the ethical issues that concern medical decision making and human research.² Apart from and in addition to his status as a public figure, Moreno is well-known in the field of bioethics. Moreno has written a respected text book on clinical ethics,³ many other books⁴ and dozens of well-respected articles.⁵ He was recently appointed to the highly prestigious Institute of Medicine—an honor awarded to few non-physicians.

Because Moreno has achieved success in the fields of individual clinical medical decision making and the ethics of medical research on human populations, the story of his life encompasses all the major developments in two very large and often distinct fields. It is a tribute to the richness of this book that it is difficult to review. There is so much important information that to emphasize some chapters risks the impression of de-emphasizing others. Some of the very best portions of this book are those in which Moreno discusses his own personal experiences. Moreno's recounting of his journey from a professor of philosophy to a hospital ethics consultant, and his reflections on the relationship between the two endeavors represents a

suspecting vulnerable populations. The experiments included "feeding radiation-laced breakfast cereal to institutionalized adolescents" without their parents' consent, "exposing cancer patients to total-body irradiation, and irradiating the testicles of subject research prisoners in state penitentiaries."¹ Moreno described his discoveries in a well-received book. This led to his continuing interest in the role of the Government in human subject research. He is perhaps best known to the public for refusing an unsolicited appointment to President Bush's National Human Research Protections Advisory Committee; he was quoted as rejecting the appointment because he felt that the other members did not represent a diversity of viewpoints. Rick Weiss, *New HHS Panel Makeup Draws Ire of Patient Advocates*, WASH. POST, Jan 5, 2003, at A9.

² JONATHAN D. MORENO, IS THERE AN ETHICIST IN THE HOUSE? ON THE CUTTING EDGE OF BIOETHICS 200 (2005).

³ See, e.g., JUDITH C. AHRONHEIM & JONATHAN MORENO ET AL., ETHICS IN CLINICAL PRACTICE (2000).

⁴ See, e.g., JONATHAN D. MORENO, IN THE WAKE OF TERROR: MEDICINE AND MORALITY IN A TIME OF CRISIS (2003); ETHICAL AND REGULATORY ASPECTS OF CLINICAL RESEARCH (2003); JONATHAN D. MORENO, UNDUE RISK: SECRET STATE EXPERIMENTS ON HUMANS (2001); EZEKIEL J. EMANUEL & JONATHAN MORENO ET AL., JONATHAN D. MORENO, DECIDING TOGETHER: BIOETHICS AND MORAL CONSENSUS (1995); and JONATHAN D. MORENO, ARGUING EUTHANASIA (1995).

⁵ Most recently Moreno questioned the value of bioethics in the face of the glaring inequalities of access to health care exposed in New Orleans after Hurricane Katrina. See, e.g., Jonathan D. Moreno, *In the Wake of Katrina: Has "Bioethics" Failed?*, 5 AM. J. BIOETHICS W18 (2005).

rich resource to all current and aspiring clinical bioethicists. His chapters recounting the history of medical research on human beings and how it came to be regulated in the United States are meticulously researched and beautifully written.

The following chapters, on specific problems in human subject research with vulnerable populations and on the current recognition of the need for protection of the cognitively impaired, are also models of clarity. These will become required reading for anyone seeking to understand how the history of human subject research impacts the current state of regulation and seeking to evaluate the effectiveness of these regulations in contemporary society.

But this book is far more than a memoir, a précis, a history, a bedside guide to bioethics, or a reflection on contemporary problems in bioethics. It is an important work of philosophical and sociological thought on the role of the philosopher in bioethics and the role of medical research in society. Moreno takes on the ambitious projects of securing bioethics' place in the history of Western Philosophy and of linking the history of human subject research regulation to the social history of the United States. He shows how bioethics is rooted in the American-developed philosophy of pragmatism and how the growth of regulation of human subject research tracked an erosion of trust in authority during the 1960's and 1970's. Given the depth and richness of this book, I approach my task as a reviewer as first highlighting the achievements of this work and then by reflecting on what it offers to the readers of a journal on health law. In so doing, I take advantage of the privilege of an academic reviewer to apply the book in a way not specifically contemplated by the author.

One of the many ways this book succeeds is, as noted above, as a sensitive memoir of the personal events which shaped Moreno's remarkable empathy for the vulnerability of human beings in the face of illness. What becomes clear in this book is that Moreno's understanding of the sick, and especially of the cognitively impaired, goes back to his experience as a child where he grew up on the grounds of a private psychiatric hospital run by his father.⁶ There, Moreno knew the patients as friends and saw their vulnerability to the good-will of those who had charge of them.⁷ He also attributes his first thoughts about bioethics at the end of life to his feelings of doubt about whether

⁶ J. L. Moreno, a prominent, Austrian trained psychiatrist who ran the Moreno Sanitarium in Beacon, New York.

⁷ See MORENO, *supra* note 2, at 154-56.

his family understood and correctly carried out his father's wishes to forgo further medical care after what would become a fatal stroke.⁸

He writes that his later work, teaching ethics to medical students and consulting in an academic medical center was, and continues to be, impacted by his understanding that it is human nature to see the sick and the vulnerable as "others" because of the inherent fear we all have of becoming like them.⁹ This fear is based on the reality that we will all become sick and will depend on others for our care, our comfort and, eventually, to manage our deaths. Moreno is exceptional in his ability to embrace this realization of what will be our common experience and apply it in the service of others. This ability combined with a powerful intellect and an unusual talent to convey subtle and complex ideas in writing and in speech have made him a highly honored teacher, scholar, member of the bioethics community and one of the most important voices in the contemporary debate over medical and research ethics.

In this book, Moreno shares aspects of his life with the reader. As a teacher, he presents clearly written and exhaustively researched histories of bioethics in the context of both medical decisions made about individuals and large-scale human subject research. He similarly presents current developments such as the role of bioethics in times of war and the much belated movement to provide protections for the cognitively impaired. As a scholar and philosopher, Moreno firmly places clinical bioethics into the tradition of Western Philosophy and shows how it is an important part of the uniquely American philosophy of pragmatism as developed by William James, John Dewey and Charles Pierce.¹⁰ He further shows how bioethics uses the method of Naturalism, which privileges the experience of the philosopher over the application of abstract forms and concepts.¹¹ As a prominent member of the community of bioethicists, he addresses the role of the bioethicist in the hospital setting. He identifies the inherent tendency to identify with the doctors and medical staff, who become friends, rather than to maintain the viewpoint as an outsider or patient advocate.¹² He also discusses the criticism that bioethicists lose their ability to provide objective analysis when they are paid for their services, either by the

⁸ See *id.* at 35-36.

⁹ See *id.* at 26-32.

¹⁰ See *id.* at 49-50.

¹¹ See *id.* at 51-66.

¹² See MORENO, *supra* note 2, at 15-32.

medical centers that employ them or by the increasing number of private companies that seek to employ ethical oversight boards.¹³

Finally, in his role as a public voice, he explains the history of both clinical and research bioethics as being closely linked to the social climate of the United States. He identifies bioethics as a “child of the sixties” in that it values individual over societal rights and seeks justice for otherwise marginalized members of society.¹⁴ By putting bioethics in the context of social history, he shows that the trend towards greater protection for human research subjects and greater respect for individual patient autonomy are not inevitable, but rather, can and are likely to change should the United States experience severe resource shortages, alone or accompanied by real threats to National Security. Moreno ends the book by speculating that the fear of terrorism brought on by the September 11, 2001 attacks on New York will result in greater interest in public safety and in less individual protection.¹⁵ His speculation is founded on how the United States has reacted to past threats to national security by conducting what were at the time secret human experiments.¹⁶ He continues to be a careful observer of the balance between the interests of the individual and society.

In Part One “A Hospital Philosopher,”¹⁷ Moreno relates his personal journey from professor of philosophy to bed-side ethicist. Although he attributes the career shift in part to being in the right place at the right time, he turns his remarkable powers of self-reflection and analysis to understanding what it meant for him to move between these two very difficult worlds. Was he a philosopher? A teacher? A healer? Moreno’s account of what he learned the medical staff needed from an outside “ethicist” is a blueprint for those entering the field today and also a warning of the inevitable shifting of boundaries when one moves from being an observer of medical decision making to a participant.

In Part Two, “Naturalizing Bioethics in Theory and Practice,”¹⁸ Moreno does no less than anchor bioethics in the American school of philosophical pragmatism. He creates a provenance for a subject that has long struggled to define itself within the world of philosophy, which views bioethics’ interest in the “real” as evidence of its lack of

¹³ See *id.* at 245-47.

¹⁴ *Id.* at 234.

¹⁵ See *id.* at 240-42.

¹⁶ See *id.* at 236.

¹⁷ See MORENO, *supra* note 2, at 3-45.

¹⁸ See *id.* at 49-101.

intellectual rigor. That will no longer be possible after this book's placement of Bioethics in Western philosophy.

Moreno begins his quest to locate the bedside clinical ethicist in the context of philosophy with the observation that "This encounter with sickness is extraordinarily challenging for one whose primary professional identification is that of philosopher, for the intellectual detachment usually associated with philosophical speculation is at least as difficult to sustain in the oncology unit, for example, and may even seem voyeuristic."¹⁹ He rejects the charge of voyeurism, however, by noting that rather than seek out this close contact with the sick, "we [philosophers] have been fairly dragged into the fray by beleaguered doctors" who are struggling to balance the new emphasis on patient autonomy with rapid growth in the available medical interventions.²⁰ Moreno writes that the reason doctors feel beleaguered today is that along with rapid advances in medical knowledge and technology that allow doctors to make far more effective interventions have come "during a period in which self-determination has also asserted itself in an equally unprecedented manner, the most obvious expression of this trend being the various civil rights movements."²¹

Moreno traces the problem of the relationship between the goals of philosophy and that of medicine back to the earliest recorded intersections between the two, noting that "Plato's Socrates frequently expressed skepticism about the usefulness of a call on the physician. Yet tradition has it that, just before his death, Socrates asked that one of his students give an offering to Aesculapius, the god of healing arts."²² Moreno sees bioethics as firmly rooted in the Socratic Western

¹⁹ See *id.* at 22.

²⁰ *Id.* The literature of physician "belaguerment" is vast. For example, in 1998 Professor Fran Miller pointed out the stress to physicians brought on by the rapid change of their role from trusted authority figures, with an essential monopoly on what "precious little" knowledge they had about how to cure disease, to that of being challenged by patients with greater skill at accessing cutting-edge medical information [from the internet]. See Frances H. Miller, *Health Care Information Technology And Informed Consent: Computers And The Doctor-Patient Relationship*, 31 IND. L. REV. 1019, 1024 (1998); see also Catherine T. Struve, *Doctors, The Adversary System, and Procedural Reform in Medical Liability Litigation*, 72 FORDHAM L. REV. 943, 948 (2004)(recounting physicians' perception of being under siege by malpractice litigation fueled by improvements in medical knowledge and technology that have heightened consumer expectations, and have led to lawsuits over imperfect results where previously—under less sophisticated treatment—no suit would have been possible).

²¹ *Id.* at 28.

²² MORENO, *supra* note 2, at 22.

tradition as reflected in the “contextual approach to moral theorizing” which the “major philosophical theorists in the 1980s” such as Richard Rorty and Alasdair Macintyre, were claiming was necessary to free moral philosophy from the reductive process of developing conclusions based on an abstract, Platonic concept of “the good.”²³

Moreno frames the questions that “emerge from this novel relationship between philosophy and medicine” as: “First, does this experience, fascinating as it may be on other counts, have anything to contribute to the ancient line of philosophical inquiry *per se*?” and “Second, what exactly the philosopher *quo* philosopher is contributing at the bedside.”²⁴ His answer to these questions in the remainder of part two is destined to become a foundational document for those seeking to place reflection on medical decision making for individual patients as a branch of “moral philosophy” in the American twentieth-century movement of “pragmatic naturalism.” Moreno explains that the bioethicist must be an activist philosopher participating in the experiences about which he is called upon to evaluate in ethical terms.²⁵

In Part Three “Human Use,”²⁶ Moreno limns the history of human subject research in the United States and explores the contemporary debates on protection of vulnerable populations. He accomplishes this by describing the contemporary situation in which human subject research is governed by Federal and State Law and enforced by agencies and persons outside of the research community. In the first section, “Goodbye to all that: The End of Moderate Protectionism in Human Subjects Research,” he states that his goal is “neither to challenge nor defend” the current state of regulation but “[r]ather, to note how inured we have become to this grim view of investigator discretion and how far we have traveled to reach this pass.”²⁷ He divides the history of oversight or regulation of human subject research in the United States into three periods: weak protectionism, moderate protectionism and strong protectionism.²⁸ He writes that he uses the term “protectionism” to mean “the view that a duty is owed those who participate as subjects in medical research.”²⁹

²³ *Id.* at 26.

²⁴ *Id.* at 22.

²⁵ *See id.* at 50.

²⁶ *See id.* at 105-172.

²⁷ MORENO, *supra* note 2, at 111.

²⁸ *Id.* at 110-11.

²⁹ *Id.* at 126.

He goes on to state, "The underlying problem is how to resolve the tension between individual interests and scientific progress, where the latter is justified in terms of benefits to future individuals."³⁰ Within that definition, he defines "Weak Protectionism" as "the view that this problem is best resolved through the judgment of virtuous scientists."³¹ Thus, under Weak Protectionism there is no outside oversight of medical research except whatever professional norms develop within the culture of physicians and scientists. Weak Protectionism characterizes the history of human subject research in the United States until the revelations of the horrific actions of physicians in Nazi Germany, which were revealed in the war crimes trial at Nuremberg.

Moreno's concise but rich account of the history of human subject research should be required reading for everyone interested in the history of human subject research. It is easy to view the history of human subject research as a series of horrendous ethical lapses,³² followed, upon discovery, by sweeping denunciations and new regulations intended to prevent all future abuses. Moreno's account, however, shows that the reality is far less clear cut. For example, Moreno shows that American physicians and scientists were immediately dissatisfied with the "legalistic" requirements of the Nuremberg Code which demanded informed consent from all research subjects, and this requirement was almost immediately softened in the 1954 declaration of Helsinki to allow for researcher discretion.³³

Moreno explains that rather than seeing the excesses of the holocaust as a danger that could befall any one, the United States medical community insisted that protections against acts by Nazi's were not needed by men of good character like themselves.³⁴ This inability or refusal to see the way real commonality between the

³⁰ *Id.*

³¹ *Id.*

³² See e.g., The Tuskegee Syphilis Study, the deprivation of poor, Black sharecroppers of life-saving penicillin in order to study the natural course of syphilis. See Wikipedia, Tuskegee Syphilis Study, at http://en.wikipedia.org/wiki/Tuskegee_Syphilis_Study (last visited Apr. 6, 2006) (a clinical study, conducted around Tuskegee, Alabama, where 400 poor, mostly illiterate African American sharecroppers became part of a study on the treatment and natural history of syphilis. This study became notorious because it was conducted without due care to its subjects, and led to major changes in how patients are protected in clinical studies. Individuals enrolled in the Tuskegee Syphilis Study did not give informed consent and were not informed of their diagnosis; instead they were told they had "bad blood" and could receive free treatment).

³³ MORENO, *supra* note 2, at 123.

³⁴ See *id.* at 198-99.

medical experiments of the Nazi period and the prevailing western norms is reflected in consistent chafing against what are often described as “legalistic” regulations that are not relevant to scientists with good moral character and will not stop scientists who lack good moral character.³⁵

In the fourth part of his book,³⁶ Moreno reminds the reader that the U.S. has been in an almost constant state of war, the Cold War, since the end of World War II. In that context, he details how the Pentagon has always chafed against human subject research regulation seeing it as a threat to their efforts at providing for national defense. Moreno uses clear, clean prose to take the reader through the most difficult and troubling historical incidents of human subject research on “convenient and captive” populations³⁷ and shows how the same ethical issues exist today as those present when Walter Reed was first conducting Yellow Fever studies on workers digging the Panama Canal. Moreno does not, however, present this history as a tale of the “bad old days” but rather addresses head-on the central problem of human subject research; that it “is a complex, expensive and valued social activity [and that] [o]ne of the conditions that makes it possible is a subject population that is convenient, both in terms of availability for recruitment and for monitoring through the course of a study.”³⁸ He notes that “[o]ne element that crops up repeatedly in the research context is that human subjects are often used in research that is not intended to benefit them but instead other individuals.”³⁹

Likewise, a population may be used in studies that develop treatments intended mainly, or even exclusively, to benefit other groups. Any reasonably well-formed conception of justice in research will need to reckon with these special circumstances.”⁴⁰ He reminds us, however, that “much human-subject research has contributed greatly to human well-being and has been conducted according to sound ethical standards.”⁴¹ By putting research performed on vulnerable or captive populations into the context of scientifically valid efforts by careful researchers to develop new, effective treatments for serious diseases, Moreno avoids presenting this history as some sort of

³⁵ See *id.* at 176.

³⁶ See *id.* at 175-207.

³⁷ See *id.* at 131-36 (referencing prisoners, institutionalized persons, military personnel, students, and employees of research institutions).

³⁸ MORENO, *supra* note 2, at 129.

³⁹ *Id.* at 131.

⁴⁰ *Id.*

⁴¹ *Id.*

*Island of Dr. Moreau*⁴² parade of horrors presided over by scientists with little or no concern about the well-being of their subjects.

Moreno describes contemporary regulation of human subject research as being “[t]he essence of strong protectionism [which is] the minimization of clinical researchers’ discretion in governing their conduct with regard to human subjects.”⁴³ This is achieved by “third-party monitoring of consent and study procedures, disclosure of financial arrangements or other potential conflicts of interest, required training of investigators in research ethics and research regulations, and independent review of the decision-making capacity of potential subjects.”⁴⁴ Moreno recognizes that all research using humans involves the inherent conflict between the needs of the many and the rights of the few. Although it is sometimes confusing that human subject research is in the purview of both clinical medicine, concerned with individuals, and public health, concerned with populations, Moreno shows why this must always be so. He returns to this at the end of the book where he speculates whether the fear of terrorism created after the events of September 11th, 2001 will result in a backlash against human subject protection.⁴⁵

He writes that:

A new preoccupation with “homeland defense” and a renewed respect for the professionals engaged in these efforts, including the granting of greater legal flexibility for espionage activities, could easily spill over into an enhanced image for civilian institutions whose mission is to protect our national survival and therefore less concern about protecting the individual rights of individuals.⁴⁶

He further speculates that this lessened concern about individuals could change views about disproportionate allocations of health care resources on “moral strengths.”⁴⁷ This concern about the role of bioethics in a time of war is an on-going theme in his current research

⁴² H.G. WELLS, *THE ISLAND OF DOCTOR MOREAU* (Leon Stover ed., McFarland 1996) (1896).

⁴³ MORENO, *supra* note 2, at 110.

⁴⁴ *Id.*

⁴⁵ *See id.* at 240-42.

⁴⁶ *Id.* at 237.

⁴⁷ *Id.*

and is reflected in writings published subsequent to this book.⁴⁸ Moreno suggests that if indeed human subject protection is weakened it will be consistent with what has happened in the United States during other periods of perceived national danger, such as the cold war.⁴⁹

Reflecting further on the pressures of bioethics in wartime, the chapter "The Meaning of Nuremberg" raises what continues to be a troubling bioethical issue of the current war on terrorism: the role of physicians in the conduct of war. Moreno shows how "The Pentagon's ambivalent relationship with Nuremberg Code" has resulted in constant tension between the Code's emphasis on openness and consent and the military's need for secrecy in pursuit of national security.⁵⁰ He also returns to the theme of the relationship between human subject protection and fears about national security. Following his book about the human radiation experiments,⁵¹ he was often asked by what he then considered "conspiracy" theorists whether there were "secret" human experiments being carried on.⁵² At the time he did not think this possible.⁵³ However, hearing that the US had developed a strain of anthrax previously linked to the Soviets, he expresses doubt.⁵⁴ Given the news that there are "secret" US interrogation prisons in Eastern Europe, it is not difficult to conclude that these same pressures have resulted in secret human experiments.⁵⁵

As this was being written, in February 2006, the American tendency to question authority proved to still be vigorous even in the face of foreign threat. There is vigorous debate over the use of torture even though there is little doubt that the US faces serious threats from terrorists. Further, it seems likely that we will eventually be hearing revelations about experiments or research intended to find the most effective torture methods. As the debate on the morality of torture and, in particular, the role of the medical profession in conducting torture continues,⁵⁶ Moreno's voice will be an important for seeking a rational

⁴⁸ See, e.g., Jonathan D. Moreno, *Detainee Ethics: Terrorists as Research Subjects*, 3 AM. J. BIOETHICS W32 (2003); Jonathan D. Moreno, *In the Wake of Katrina: Has "Bioethics" Failed?* 5 AM. J. BIOETHICS W18 (2005).

⁴⁹ MORENO, *supra* note 2, at 236-37.

⁵⁰ *Id.* at 177.

⁵¹ JONATHAN D. MORENO, *UNDUE RISK: SECRET STATE EXPERIMENTS ON HUMANS* (2001).

⁵² MORENO, *supra* note 2, at 236.

⁵³ *Id.*

⁵⁴ *Id.* at 235.

⁵⁵ See Robert Jay Lifton, *Doctors and Torture*, 351 NEW ENG. J. MED. 415-16 (2004).

⁵⁶ *Id.*

balance between fears about national security and the danger of losing the hard-won American belief in the value and dignity of all human beings.

Finally, part Five of Moreno's book⁵⁷ considers various challenges to bioethics, many of which come from advances in both medicine and technology, including the ability to read an individuals' genetic code. Moreno considers his own mortality in a new way as he reflects upon his fortieth birthday and speaks quite candidly about his mother's struggle with cancer.⁵⁸ Specifically, he comments on the changing relationship between the physician and the patient and how a physician who almost routinely uses the word "cancer" with their patients today would never have done so forty years ago, choosing a more placating euphemism such as "growth" instead.⁵⁹

In his next chapter, Moreno discusses the impact that neuroscience has had on society, and specifically the law, with regard to selective serotonin reuptake inhibitors and traumatic brain injury and their implications from the standpoint of determining criminal culpability.⁶⁰ In this chapter, Moreno also addresses a growing concern of his and of the research community's with the lack of regulation for research with individuals whose cognitive impairments make it difficult for them to give informed consent. In doing so, he proposes adding "impaired consent" to the list of legally protected vulnerable subjects.⁶¹ He writes that although medical testing on those with impaired "decision making abilities" is not a new issue as institutionalized persons have always been attractive subjects because of their confinement and ability to be monitored.⁶² He also looks at what has become another area of growing concern, which is decision-making by the cognitively impaired. These patients are often researchers' favorite subjects to further advances in Alzheimer's and other such illnesses, but the fact remains that these patients are cognitively impaired and are perhaps unaware of the ramifications of participating in such research. Moreno therefore presents a very serious issue for incapacitated adults, which is the uncertainty of *who* may authorize such research if these patients cannot.⁶³

⁵⁷ See MORENO, *supra* note 2, at 211-50.

⁵⁸ *Id.* at 213.

⁵⁹ *Id.* at 214.

⁶⁰ *Id.* at 224-225.

⁶¹ *Id.* at 227.

⁶² MORENO, *supra* note 2, at 228.

⁶³ *Id.*

In closing, he addresses a contemporary dispute among bioethicists as to the propriety of serving as paid advisors to commercial entities seeking to develop new medical drugs and devices.⁶⁴ As expected, Moreno confronts the most substantial critique of this practice, which is that bioethicists are induced to promote a product because of their financial incentive and therefore their “advisement” is motivated more by their financial gain than their expertise.⁶⁵ Moreno then disclosed his own personal experience in serving on a similar board and conveys that he shares a similar perspective as those who defend this practice, which is that “no respectable ethics expert would allow his or her opinion to be bought” and that the problems, which drive corporations to seek ethics advice, are in fact genuine.⁶⁶

The Role of the Lawyer-Bioethicist

Since this review is written for a law journal and therefore will most likely be read by law students and lawyers interested in clinical ethics, I will give most emphasis to how Moreno’s work can inform the role of the “lawyer-ethicist.” In so doing, I will also take advantage of the privilege an academic book reviewer has to apply the book in a context, in this case the lawyer-bioethicist, which is not the primary intent of the author. This book is written by a philosopher about the role of philosophy in bioethics, particularly the practice of bioethics. Moreno makes almost no mention of lawyers in his book except to note that although legal training imparts many of the same important skills as philosophy, the natural distrust of lawyers by doctors makes the lawyer somewhat less effective than a philosopher in conducting bioethics consults.⁶⁷ In writing about the advantage of his role as a philosopher, he cites “specific advantages for the philosopher as compared to the lawyer in this role, for lawyers are commonly so stereotyped by physicians that it can be difficult for them to be heard as sympathetic or at least neutral. Philosophers can occupy a certain moral high ground, the same high ground that theologians used to be able to claim.”⁶⁸ By implication lawyers lack “moral high ground,” which impairs their credibility to physicians.

⁶⁴ *Id.* at 245-47.

⁶⁵ *Id.* at 245.

⁶⁶ *Id.*

⁶⁷ See MORENO, *supra* note 2, at 29.

⁶⁸ *Id.*

I feel comfortable applying Moreno's experience and observation to those with legal training because he, himself asserts that the qualifications of a successful bioethicist are not particular to Philosophers.⁶⁹ This is based on his answer to the question he poses early in the book in a section called "Who Teaches Virtue" when he considers the typical dual roles of the bioethicist in an academic medical center. That role involves not just consulting at the bedside but also teaching ethics to medical students.⁷⁰

Now what uniquely qualifies philosophers to take on this educational job [educating medical students about ethics]?" The answer ... is nothing uniquely qualifies the philosopher. Anyone comfortable with the free play of ideas, capable of formulating and assessing arguments, sensitive to connections between seemingly unrelated subjects, and with sufficient intellectual curiosity and self-confidence to become engaged with a variety of technical languages, can take this on. It does happen that, among the academic disciplines, philosophers are likely to have been trained specifically in the acquisition of these skills and to be self-selected in the possession of the necessary qualities (Moreno, 1991). Clearly, however, individuals from a variety of backgrounds, including law, medicine, or nursing, could be equally qualified."⁷¹

He notes, however, that lawyers may not be effective because there are specific advantages for the philosopher as compared to the lawyer in this role because "lawyers are commonly so stereotyped by physicians that it can be difficult for them to be heard as sympathetic or at least neutral."⁷² At another point, he notes that the contribution of a lawyer is limited because there is already a defined role for the hospital's lawyers in an ethical dispute—presumably to shield the hospital from liability.⁷³ Indeed, this is a job of the hospital's lawyer, but it is accomplished every day either by highly skilled individual lawyers who can separate their roles as ethicist and risk manager or by involving two or more lawyers.

⁶⁹ See *Id.* at 28.

⁷⁰ See *Id.* at 26.

⁷¹ *Id.* at 28 (emphasis added).

⁷² MORENO, *supra* note 2, at 29.

⁷³ See *id.* at 19.

Moreno's list of desirable traits in a clinical ethics consultant also point to the value of legal training. Moreno notes that "one must be acquainted with relevant statutory and case law, the institutional structure of the healthcare system, the financing of health care, and the prevailing consensus and current issues in health policy."⁷⁴ In reflecting on those "aspect[s] of my philosophical education that is most helpful is the ability to analyze a conceptual problem in a way that may clarify the issues."⁷⁵ He states that to be effective in "work[ing] on ethical problems directly with health care professionals in the real setting of healthcare delivery requires a further range of skills that have little to do with traditional training in any single discipline, including philosophy."⁷⁶ In addition, "some understanding of the economics of health care is very useful, and an appreciation for the sociological and political processes of the clinical setting is essential."⁷⁷ It is no wonder then that Moreno later describes being a bioethicist as an "impossible profession."⁷⁸ Moreno draws an analogy to the observation that "psychoanalysis [is] the impossible profession" because "[h]ow could anyone hope to see into the psyche of another, apart from the vantage point of one's own?" by describing the competing and conflicting demands on the bioethicists as equally impossible.⁷⁹

We are expected to be original scholars not only in our own basic disciplines but also in connection with issues in health care. As humanists addressing clinicians and scientists, we are also expected to speak with authority on the economics and politics of health care, the system for allocating resources, the psychology of physician-patient relations, and the culture of medicine, among other diverse topics. Who in their right mind would take this one?⁸⁰

While the definitive history has yet to be written, lawyers in their capacity of hospital counsel have probably been consulted on difficult bioethical issues for as long as such issues have presented themselves. It has been my personal experience that doctors are able to

⁷⁴ *Id.* at 31.

⁷⁵ *Id.* at 30.

⁷⁶ *Id.* at 31.

⁷⁷ MORENO, *supra* note 2, at 33.

⁷⁸ *Id.* at 243.

⁷⁹ *Id.*

⁸⁰ *Id.*

make the distinction between lawyers in general and an individual lawyer who is sympathetic to both the very real pressures of having responsibility for the life and well-being of another human and the medical team's deep personal commitment to their patients. Perhaps this is because many doctors have family members who are lawyers and are therefore prepared to accept the possibility that a lawyer is there to help. Finally, and perhaps most helpfully, my experience is that along with the fear doctors have of lawyers there is also a respect for our training in analyzing complex problems and our ability to put thoughts into words. Although it may not be comfortable to be viewed as one of the few "good" or "trustworthy" lawyers, the fact is that the role is sufficiently established to allow the lawyer-ethicist a voice at the table.

Further, Moreno's observations about philosophers are more closely analogous to that of lawyers than to bioethicists with medical training. Both lawyers and philosophers must address the primary question of how someone trained outside the medical fraternity can be of use. Moreno defines the work of the ethics consultant as influencing policy rather than simply solving a series of individual problems.⁸¹ Lawyers, too, can and do play this role of "policy scientist" or "policy humanist."⁸² In this context, Moreno's thoughts, informed by nearly 20 years of experience in this role, are critical to anyone who wants to take on the role of an "ethics expert" in the process of making decisions for other human beings, which arise in a medical context.

Since, of course, Moreno is not writing about the lawyer-bioethicist, he does not address what is really the primary problem for a lawyer in this situation, which is not that her ideas will be dismissed, but rather that she will be asked to solve the problem by "saying what the law is." Given all their supposed hostility to the law and lawyers, I have found doctors have a completely baseless confidence that there is a definitive legal solution to every problem. The unfortunate truth, which every lawyer dealing with doctors must learn to convey, is that the law establishes boundaries but does not prescribe solutions. In reality, the actual legal issues that arise in bedside clinical ethics are usually so well settled that their resolution plays no role in resolving the issue. If these problems had solutions dictated by law there would be no role for ethical consultation beyond communicating the result to the family.

⁸¹ *Id.* at 65.

⁸² MORENO, *supra* note 2, at 65.

It is often the role of the lawyer-bioethicist to clarify for the medical team what, exactly, is meant by the concept of law and the legal system in the United States. First of all, it is important for all lawyers to remember that no matter how many legislators or their aids have legal degrees, lawyers do not make the law. Laws, according to the Constitution, are made by the directly elected representatives of the American people, enacted by the President who is elected through the Constitution's provisions for an electoral college and enforced by citizen juries and, what is in many states the directly elected, judiciary. Thus, every lawmaker casting her vote is in fact representing a very specific, geographically based population of individuals who have voted her into office and can just as easily vote her out. A practicing attorney, even the much maligned "trial lawyer," can do no more than form and present arguments based on existing laws.

The second function of the law is to adjudicate disputes between individuals. The power of judges and juries to make binding decisions is delegated to them by society, the same voting public. The law, then, is not imposed on society but rather created by it. The role of law in resolving an issue of patient care is, therefore, completely dependent on whether the issue is law as "prescriptive limit setting," for example outlawing physician assisted suicide, or law as "dispute resolution," such as determining which family member will be allowed to make a decision about terminating life sustaining treatment. Unfortunately, the most bitter disputes arising around medical decision making come from the need to resolve disputes among family members.

The *Terri Schiavo* case which gripped the nation last year is, unfortunately, a quite typical example of how the law shapes medical decision making.⁸³ The representatives of the citizens of the state of Florida adopted the law which determined that a husband could make medical decisions for his incompetent spouse.⁸⁴ Floridians also adopted the judiciary system which determined that Michael Schiavo was Terri Schiavo's lawful husband, that she had not designated any

⁸³ See generally Steven G. Calabresi, *The Terri Schiavo Case: In Defense of the Special Law Enacted By Congress and President Bush*, 100 NW. U.L. REV. 151 (2006); see also *Schindler v. Schiavo*, 780 So. 2d 176, 26 Fla. L. Weekly D 305 (2001); *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161, 18 Fla. L. Weekly Fed. D 375 (2005). See generally University of Miami Ethics Programs, http://www.miami.edu/ethics/schiavo_projects.htm (last visited Mar. 6, 2006). See also *Robert Schindler v. Michael Schiavo ex rel. Theresa Marie Schiavo*, 789 So.2d 348 (Fla. 2001).

⁸⁴ FLA. STAT. ch. § 765.401 (2000).

other decision maker and that he was following her wishes in removing the feeding tube that was keeping her alive.⁸⁵ The only role for an ethicist in such a dispute is to attempt to reach a compromise between warring family members. Barring agreement, the family's dispute must be referred to some outside form of decision making.⁸⁶ Moreno writes that he discovered early in his career as an ethics consultant that "More often than not, the problem with a current case has to do with a concern or disagreement with a patient's family about the most appropriate course of treatment."⁸⁷ The frequency with which these disputes arise leads Moreno to list "sound interpersonal skills, particularly tactfulness and the ability to mediate among deeply felt differences while honoring them" as a quality which "can vastly enhance the value of the ethics consultant."⁸⁸

So what is the role of the law in resolving clinical bioethical dilemmas? It is that the parameters within which ethicists work in issues such as physician assisted suicide are based on laws created by society, not by lawyers. If individual voters in an individual state wish to allow physician assisted suicide then it is their prerogative to enact a law such as Oregon's.⁸⁹ The fact that except for Oregon no state allows physician assisted suicide is not an artifact of fancy lawyering; it is the will of the people.

Therefore, absent a practice prohibited by specific law, the law does not affect medical decisions. Indeed, the law offers so little help in most situations that many hospitals have their own "folk" beliefs about the law, which, not coincidentally, foster their administrative needs. For example, no state has a law specifying when a hospital must remove the equipment which had been sustaining the physical body of a patient after he is declared brain-dead. The law establishes criteria for brain death and is then silent. Routinely, however, hospitals will

⁸⁵ The legal drama was Congress' decision to preempt the fact finding role of the Florida state courts and giving it to the Federal court system.

⁸⁶ Although there is within bioethics a movement to resolve family disputes by mediation rather than adjudication, it is inevitable that as in the case of the Schiavo family some disputes will be left to the courts. See generally NANCY NEVELOFF DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS* (2004).

⁸⁷ MORENO, *supra* note 2, at 13.

⁸⁸ *Id.* at 31.

⁸⁹ The Oregon Death with Dignity Act, OR. REV. STAT. § § 127.800-.897 (2003) (permitting physicians to prescribe lethal doses of controlled substances to terminally ill residents of Oregon, but also utilizing certain procedures intended to protect those not "capable" of making an "informed decision").

hurry along families by telling them “by law” they must remove their loved one from the machines and refer the “corpse” for burial. This was evidenced in the debacle at Duke University Hospital when the mother of Jessica Santillan, the 12-year-old girl who due to medical error received incompatible organs, was told that the law required Jessica to be removed from the machines within hours of her being declared brain dead.⁹⁰ Lawyers are often criticized for discussing this gap in the law in public because of the “harm” it would cause families to know that if they had the money and the inclination they could keep their brain-dead child’s body oxygenated indefinitely. What these always extremely well-meaning clinicians seek to avoid is an ugly confrontation with a grieving family in which the hospital must acknowledge that it is no longer willing to provide the patient with a bed. Therefore, unless the family can, at their expense, find a facility willing to accept the patient, the patient will be disconnected from the machines and transferred to a funeral home for burial. Clearly this will create hard feelings at the bedside, but it will not be because of the hospital’s requirement to follow the law.

So if knowledge of the law itself is not a necessary skill to solving most of the morally difficult decisions that arise when there is no chance of a medical cure, yet no prospect of imminent natural death, what is the role of an ethics consultant—whether she is a lawyer or philosopher or nurse? Moreno accurately identifies that often the most valuable role of the consultant is to provide a perspective outside of the medical model. The consultant, he writes, is the person without medical training who can see the situation as the patient herself might.⁹¹ This truth, the role of the ethicist as a sympathetic outsider, is to me the true value of including outside clinical ethicists in high stakes decision making. The role of the lawyer, as an outsider, is one of our greatest contributions. Reading Moreno’s accounts of his early experiences as a consultant in bioethics reminds me of a series of 19th century children’s stories⁹² which center around the power of the outsider in solving seemingly intractable problems. The stories concern the Peterkins, a large family consisting of a mother, father and six children.⁹³ The Peterkins were intelligent, educated, kind hearted

⁹⁰ See generally Jean P Fisher, *Duke University Health System Maintains Financial Health*, NEWS & OBSERVER, Oct. 6, 2005.

⁹¹ See MORENO, *supra* note 2, at 29.

⁹² LUCRETIA P. HALE, *THE PETERKIN PAPERS* (The Riverside Press Cambridge 1960) (1914).

⁹³ See generally *id.*

people who often found themselves in dilemmas from which they could not, as a group, extract themselves.⁹⁴ On one notable occasion, Mrs. Peterkin put salt instead of sugar in her coffee.⁹⁵ This, of course, rendered it undrinkable. One by one, members of the family attempted to solve the problem by adding ingredients they hoped would turn the increasingly foul liquid back into coffee.⁹⁶ Finally, at desperation's edge, they turned to what would become their final resort in all such situations: they summoned "The Lady from Philadelphia."⁹⁷

Never named further, "The Lady from Philadelphia" was a family friend with no special expertise or other training.⁹⁸ Yet on this occasion, as on many others, she knew exactly what to do.⁹⁹ On arrival, she suggested that Mrs. Peterkin spill out the noxious brew, wash out the cup and pour a new cup of coffee.¹⁰⁰ Immediately the problem was solved and all were delighted.¹⁰¹ No one felt stupid, nor was there ever any indication that the Peterkins lacked normal problem solving abilities or common sense.¹⁰² Rather, they became enmeshed in a group decision making process from which they could see no way out. Only a sympathetic outsider with no personal stake in creating the problem could recognize a solution with which all were happy.

Without trivializing the role of the philosopher or lawyer ethicist, it is this position as the sympathetic outsider which can be of the most use in solving a problem that has evaded resolution through the normal model of medical decision making. Moreno provides a perfect example of the ethicist as thinking outside of the prevailing paradigm in recounting a solution devised by his friend, noted bioethicist Art Caplan, a philosopher from Philadelphia.¹⁰³ Faced with an emergency room overwhelmed by elderly people suffering respiratory effects of an unusual heat wave, Caplan asked whether Medicaid or Medicare funding could be used to purchase air conditioners.¹⁰⁴ A call to the department of social services found out

⁹⁴ See generally *id.*

⁹⁵ LUCRETIA P. HALE, *The Lady Who Put Salt in Her Coffee*, in *THE PETERKIN PAPERS*, at 6 (The Riverside Press Cambridge 1960) (1914).

⁹⁶ *Id.*

⁹⁷ *Id.* at 12.

⁹⁸ *Id.*

⁹⁹ *Id.*

¹⁰⁰ HALE, *supra* note 95, at 12.

¹⁰¹ *Id.*

¹⁰² See *id.* at 6-12.

¹⁰³ See MORENO, *supra* note 2, at 71-72.

¹⁰⁴ *Id.*

that this was possible. The frail elderly were therefore kept safe and comfortable in their homes and no longer needed to seek care in the emergency room. This solution had no basis in the skills of managing an emergency department, developing cost effective treatments for heat stroke or even developing standards for rationing scarce resources. Rather, by thinking of a solution to the problem outside of the world of the hospital, Dr. Caplan was able to devise a solution satisfactory to all parties. Although most problems are not susceptible to such elegant solutions, often an outsider can make a suggestion or see an option simply because she is not tied to the medical model.

Moreno recognizes that the lawyer's or philosopher's role as an outsider is most at risk when a lawyer or a philosopher becomes a member of the "team." He writes that to be effective, the consultant must struggle against identifying with the medical team who become colleagues and friends.¹⁰⁵ This natural tendency to identify with people we spend time with can be seen as a form of Stockholm syndrome¹⁰⁶ and is especially dangerous for lawyer-ethicists who are happy to go along with their physician/friends construct because they are anxious to prove themselves a "good" lawyer and not one of the "bad" lawyers who doctors hate. We are so eager to avoid this unfair label and to prove ourselves friendly and sympathetic that we stand to lose what is our real value to the team: our status as a clear-thinking outsider.

The title of Moreno's book alludes to this role confusion, and he discusses it further by telling a story about his own tendency to "identify with the physician role." He writes that during a long airplane flight he was "struck by an urgent desire to answer the flight attendants' call for a physician to tend an ill passenger."¹⁰⁷ All of us who seek to do this difficult work must give our thanks to Jonathan Moreno for the careful, self-effacing analysis of the role of ethics consultant which he provides us in this book. As we are all patients and all beneficiaries of the medical advances from human subject research, this latest book by Jonathan Moreno earns its place as an important, rewarding, and delightful addition to the canon of works recounting bioethics' history and setting policy for its future.

¹⁰⁵ *Id.* at 15-32.

¹⁰⁶ Wikipedia, Stockholm Syndrome, at http://en.wikipedia.org/wiki/Stockholm_syndrome (last visited Apr. 6, 2006) (a psychological response sometimes seen in a hostage, in which the hostage exhibits seeming *loyalty* to the hostage-taker, in spite of the danger (or at least risk) the hostage has been put in. Stockholm syndrome is also sometimes discussed in reference to other situations with similar tensions, such as battered woman syndrome, child abuse cases, and bride kidnapping).

¹⁰⁷ MORENO, *supra* note 2, at 15.

In conclusion, the depth and breadth of *Is There an Ethicist in the House?* is an entertaining read and a valuable contribution to the field of bioethics, whether it is enjoyed by reading it straight through – as I recommend – or by dipping into specific chapters of interest. The reward will be an increased understanding of bioethics and, just as important, the opportunity to get to know an extraordinary man.